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**Dr. Nicholas Panomitros, DDS, MA, JD, LL.M.
ILHIE Data Security and Privacy Committee
Illinois Health Information Exchange Authority
100 W. Randolph St., Suite 2-201
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By eMail**

Dr. Panomitros:

Netsmart Technologies thanks the ILHIE Data Security and Privacy Committee for the opportunity to share our views on the issues and challenges facing the Illinois Health Information Exchange with respect to the protection of consumer health data.

By way of background, Netsmart Technologies provides on-demand and traditional software solutions to automate key financial, clinical, and management process solutions and electronic medical records for more than 20,000 Behavioral Health and Public Health organizations, including individual private practices, small group providers, community health centers, counties and 40 state systems. Nationwide, our systems help improve the quality of life for more than 20 Million consumers annually and deliver millions of secure and encrypted prescriptions electronically through a nationwide network. In Illinois, we are proud to have a number of providers throughout the state that rely on our systems to improve the lives of Illinois residents. We also employ a substantial workforce in our facility located in Lisle.

On behalf of our client organizations in Illinois and the consumers they serve, we applaud the efforts of the Committee and the Illinois Health Information Exchange Authority to include Behavioral Health and Substance Abuse organizations in the complete circle of providers who address consumers' Physical and Behavioral Health in Illinois through access to ILHIE. While many of the issues your Committee is wrestling with span both Physical Health and Behavioral Health, some are unique in their impact on Behavioral Health and Substance Abuse consumers. In the following text, Netsmart offers a point of view for the Committee's consideration based on our 30+ years of serving the community of Behavioral Health, Mental Health, Substance Abuse, Developmental Disability providers and Public Health agencies.

Effect of Pt. choice on HIE collection of PHI (no re-disclosure v. no collection)

In order to protect consumer privacy, prevent discrimination against consumers battling substance issues and to encourage consumers to seek treatment with confidence that their PHI is secure, providers who offer Substance Abuse treatment to consumers are governed in their ability to share consumer data by the Code Of Federal Regulations – specifically 42 CFR Part 2. In making a choice between not collecting any data at all that might be used to provide a complete program of care for consumers enrolled in SA programs or in notifying recipients of the limitations on re-disclosure, Netsmart urges the Committee to recommend a policy of notification regarding the re-disclosure of such data.

In section 2.32 of the code, the following text is defined as the federally approved notice that must accompany any delivery of data by a 42-CFR Part 2 covered organization:

This information has been disclosed to you from records protected by Federal confidentiality rules (42 CFR Part 2). The Federal rules prohibit you from making any further disclosure of this information unless further disclosure is expressly permitted by the written consent of the person to whom it pertains or as otherwise permitted by 42 CFR Part 2. A general authorization for the release of medical or other information is NOT sufficient for this purpose. The Federal rules restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse patient.

Netsmart believes that this notice could easily be attached as a header to all data that the ILHIE transmits from a 42 CFR Part 2 covered organization. In the future, a click-through electronic acknowledgement by receivers might be contemplated to support the critical nature of the privacy issues covered by this statute.

Form of exercising Pt. choice

It is Netsmart's position that both patients and providers will be best served by an affirmative consent – oral or written that is captured with appropriate safeguards. In order to experience a higher participation rate (which our client organizations believe would be of great benefit to the consumers they serve), our assessment is that more patients will participate if given the opportunity to Opt-Out rather than the choice to Opt-In. However, we are of the opinion that patients should indeed be offered a choice. We do not think it serves anyone to share patient data with respect to patients who have not exercised consent or whose guardians have not exercised consent on their behalf based on a blanket rule of share data unless

otherwise directed. Netsmart urges the Committee to recommend a position of patient consent with the choice to Opt-Out.

Manner of informing Pt. of choice ("meaningful choice")

Netsmart has taken the position that it is in the interests of consumers to ensure that all have access to the same information regarding their choices regarding the exchange of their personal health data. The best way to ensure uniform advice to all consumers is to standardize the information to be given to all consumers in a single source. This could be a website that clinicians or front desk staff refer to when advising the consumer; or some other central resource that can be updated as new terms become available. This resource should all be accessible by the patients themselves, their guardians, or to whoever is advising the patients on their choices. That would make a web site an ideal tool for consumers' own efforts to inform themselves or to facilitate uniform consultation across the State and for all consumers. Netsmart urges the Committee to recommend a position of adopting a single central source to contain all the information a consumer or their clinician might want to obtain regarding patient choice.

Granularity of Pt. choice

In the fast-evolving world of health data exchange, it is reasonable to conclude that maturing consumer choices, new technical capabilities, evolving state and federal laws, and new accountable care models and their supporting processes will shape the issue of granularity of choice over the foreseeable future. Netsmart's expectation is that consumers will demand more granularity of choice in the sharing of their data as all of the trends mentioned above impact the healthcare landscape.

Netsmart also realizes that while our own systems can handle and process a high degree of data selection, many of the systems in use in the State do not yet have the capabilities that Netsmart has developed to match data types with granular consumer consent choices. In order to facilitate the fastest benefit to consumers in the Behavioral Health and Substance Abuse settings through inclusion into ILHIE, Netsmart urges the Committee to adopt an All-In approach for the inclusion of consumer health data at the present time.

In light of our assumptions that consumer expectations regarding granularity will change in the future, we urge the Committee to develop an aspirational model of data granularity for the future – not one grounded in the least capable system in

the network today. You may want to offer vendors and provider organizations between three and five years to achieve the capabilities, processes, and practices that would allow for consumers to exercise more choice over the elements of their health record that would be shared.

From a systems vendor point of view, an important factor to consider when expanding granularity choices is to have a uniform consent standard. The systems have to be able to interpret consumer consent for different data types in an unambiguous fashion. For example if a patient does not want their '*meds*' shared, the consent has to have a universal name and format for the data fields related to '*meds*'. Without such a uniform naming convention and format, different systems could pass information labeled: '*medications, prescriptions, medicines, drugs, compounds, titrations*', etc while blocking only those fields and data labeled "*meds*".

Netsmart will be pleased to work with ILHIE and this Committee over time to help you address evolving granularity of choice to Illinois consumers regarding their ability to share some portions of their health record while keeping other portions private.

Reconciliation of conflicting pt. consents

It is Netsmart's position that with respect to conflicting consents, the format that makes the most sense is a "Latest Date Governs" model. This allows for the capture of the latest directives from consumers who change their mind subsequent to signing their original consent. This model would require the ability of systems to check consent date fields and compare them to determine most current. It would not however, relieve systems from storing and tracking previous consents as future legal actions might hinge on the form of consent the consumer had authorized at any given point in time in the past. Therefore the consent trail needs to be auditable and secure. We will need to track consent versions, values, changes, dates changed, and changed 'by who' in order to provide auditability in case of alleged improper disclosure of data. Netsmart urges the Committee to recommend a position of adopting a "Latest Date Governs" model of consent management when dealing with conflicting consumer consents.

Specially-Protected PHI Policy Decision Tree: Mental Health PHI Data, Substance Abuse PHI Data and Immunization Registry Opt-Out

While Netsmart can offer nothing more than anecdotal evidence to support this position, our client organizations are of the opinion that many more of their consumers wish to securely share their health history with other providers of care who deliver services to them than are concerned about opting out of health data sharing in order to protect their privacy. Yet, both points of view need to be accommodated. Netsmart recognizes that consumers should have a choice – either to include their data in a sharing process or to exclude it. In order to accommodate consumers in Behavioral Health and Substance Abuse settings on both sides of the sharing argument, Netsmart urges the Committee to recommend that all Illinois consumers (regardless of the type of program they are enrolled in) be offered the opportunity to participate in ILHIE under a policy of transmitting all consumer data through the HIE (provided proper consumer consent has been captured and validated).

With respect to Public Health Information our clients (Counties and States) have long recognized the benefit to the population of sharing data such as: immunizations, reportable diseases, syndromic surveillance records, etc. Indeed it happens on paper in almost every jurisdiction in the United States today. By exchanging this vital public health data through ILHIE, the same data will be exchanged - but it will be done more accurately and at lower costs to all involved. Further, technology available today can securely de-identify data so that in instances where individual identifiers are not required, identity data can be scrubbed ensuring greater privacy than current methods of sharing population-based data. Netsmart urges the Committee to recommend a position allowing exchange of public health data through ILHIE without the option to opt-out in this matter that impacts the entire population whose need (in our opinion) outweighs the needs of any single individual.

Pt. access to data at HIE

From a security point of view, Netsmart believes that data that is distributed is less likely to be susceptible to mass hacking than data that is centrally stored. With that in mind, Netsmart recommends against a centralized aggregation of data (with the exception of data and functionality required to operate a central Master Patient Index). Our position is that each provider should govern the transmission and exchange of consumer data consistent with most current consumer consent on file or received in a request. Netsmart urges the Committee to recommend a position of decentralized data management and access for ILHIE.

Permitted uses of HIE

At this stage, no one has any idea what kind of applications and benefits will evolve in the sharing of consumer health data. Netsmart believes it is prudent to adopt a stance that allows for uses of such data that cannot now be foreseen – provided those uses are governed by informed consumer consent. This should and could include the sale of data with proper consent. The data is (after all) owned by the consumer. One could easily imagine an opportunity for patients to someday sell their data for research to a group studying a disease they suffer from. Netsmart urges the Committee to recommend a position allowing any consumer health data to be used in any lawful way that is authorized by informed consumer consent.

Restrictions on permitted uses of HIE

In order to process information, the systems that allow for transmission and access to consumer data must have unambiguous standards to enforce. Examples would include: patient consent available / no patient consent available, Consent is valid / Consent expiration date has passed. These can be processed by systems because they contain values that are well-defined, are unambiguous, can be coded into the record, and can be tested by systems in a decision tree.

That is not the case with subjective terms and values such as “Minimum Necessary”. Such terms require human judgment - which means human interaction based on the circumstance. Which people get to decide what is the minimum necessary? How do they code that into the data request in order to access data? How is “Minimum Necessary” enforced after the data has been released? The fact is, “Minimum Necessary” is a subjective standard that is nearly impossible to administer through the use of automated systems. It implies a judgment on the need and scope of data that cannot be validated based on logic testing.

Netsmart urges the Committee to recommend a position against the use of subjective standards such as “Minimum Necessary” for any processes or rules associated with ILHIE.

Mechanisms to foster public trust in HIE

In reviewing all of the options offered for comment (enforcement monitoring, breach reporting to HIE by breached entities or by public whistleblowers, real time network monitoring, field audits, HIE audits of users, third party audits of users, user self-certification of audit) Netsmart has found no barriers that would prevent any of the inspection mechanisms from operating effectively. However, in discussion with our clients, we have become aware of an issue with the follow-on actions that might proceed from an audit. If the audits unearthed issues with the correctness of data, the question arises as to the method for repairing the record.

The most likely entity in the chain to find incorrect data is the actual consumer who has received services and whose information is being exchanged. Our clients caution that while the consumer might find erroneous information, the consumer can not be allowed to change the information on their record. That should be the job of the originating provider who documented the information.

Our clients point out that consumers (for their own reasons) might add immunizations that they have never received or change diagnosis information to suit their own purposes. Maybe they would eliminate notations indicating their behavioral condition poses a physical threat to self or others because they do not like the way they are portrayed. The list of potential negative outcomes that would be present in a world where consumers decided (on their own) exactly what their health record depicts is endless. The worst of these outcomes is the possibility that the medical community learns to distrust the information contained in the medical records available through the HIE.

It is the position of Netsmart and our clients that the originating provider should be the only entity in the chain that should be capable of amending or appending the original record. The deployment of a decentralized data storage model will greatly facilitate this approach.

As a note; this position that the consumer should not be allowed to alter the medical record in no way conflicts with the idea that the consumer should have informed consent as to whether or not to share their health data in whole or (in the future) in part.

Netsmart urges the Committee to recommend a position that allows for a wide range of methods to detect breaches or erroneous data. Further, Netsmart recommends the Committee recommend severe penalties for misuse or unlawful access to private consumer health data. Finally, Netsmart urges the Committee

to recommend a process by which the original provider of the data is the only entity in the chain authorized to append their original data with a correction or notation as to the correctness of the data.

On behalf of our clients and the consumers in Illinois who are receiving Behavioral Health and Substance Abuse Treatment services, we thank the Data Security and Privacy Committee for the opportunity to comment on the issues facing the creation of the ILHIE. Our goal is to create a situation where our client organizations can participate in ILHIE and stand ready to assist this Committee in the furtherance of this goal.

Cordially:

A handwritten signature in black ink, appearing to read 'R. Adams', with a large, stylized initial 'R'.

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